



## Abstract

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**PI Title:** DIRECTOR

**Project Title:** END OF LIFE PREFERENCES & OUTCOMES: PATIENTS & SPOUSES

**Abstract:** *Proposed is a prospective longitudinal study of: (1) the end of life preferences for treatment held by patients with chronic illness and their spouses; (2) the ways that end of life preference of patients and spouses change over the course of a chronic illness; and (3) the effects that end of life preferences and actual administration of various end of life treatments have on the sense of burden, grief, and mental health of the patient's spouse. The overall goal of the study is to gain better understanding of the preferences for end of life treatment and the effects of such preferences within the contexts of both the marital dyad and the course of chronic disease. Grounded in family stress theory, the central hypotheses to be tested are: (1) Patient and spouse preferences for end of life treatment vary directly as a function of perceptions of quality of patient life and indirectly as a function of the stressors (e.g., physical health and functional ability of the patient) and resources (religious/spiritual, marital relationship, social support) of patients and their spouses; (2) The greater the congruence between patient and spouse regarding end of life preferences, the less the sense of burden the spouse will feel. Reduced burden, in turn, results in better mental health for the spouse; (3) Over the course of disease, as quality of life declines, preferences for treatment will change from those focused on aggressive treatment to those that are more palliative; (4) The greater the degree of spouse congruence regarding preferences for end of life treatment and the greater the extent of congruence between preferences for treatment and actual end of life treatment administered, the less grief will be experienced by the spouse after the death of the patient and the better will be the mental health of the spouse. In order to address these hypotheses, a five-year prospective longitudinal study design is proposed. 325 patients with ESRD and*

*their spouses would be assessed comprehensively at baseline and then briefly at four times (9, 18, 27, 36 months) over the course of the three years. Spouses who become widowed during the observation period would participate in a single post-death interview. Analyses would focus on both cross-sectional and prospective longitudinal relationships using a combination of a regression, structural equation modeling, and categorical data analysis techniques.*

***Thesaurus Terms:***

*chronic renal failure, grief, preference, spouse, terminal patient care  
behavioral /social science research tag, clinical research, human subject, interview*

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